THE DEBENHAM PROJECT
Dementia - Caring for the Carers

Research into
"HELPING CARERS & CARED-FOR TO ASK FOR HELP BEFORE THE CRISIS"

Update to the Trustees & Steering Group
3rd July 2013

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The Research: Aims & Objectives

- Research project commenced in July 2012, funded by Norfolk & Suffolk Dementia Alliance

- **Aim**: investigate what encourages or discourages families and carers in the Debenham area to seek early support and diagnosis for memory loss and dementia

- **Objective:** inform Debenham Project and partners to contribute to robust planning of future services/support locally and potentially across the area

The Research: Context

- Government agenda:
    - Increased dementia diagnosis nationally from existing 45%
    - Diagnosis to act as gateway to treatment, care/support & other services
    - 20 Dementia-friendly communities in UK by 2015
- Debenham Project:
    - A *local community-inspired & based* dementia support project

      “Dedicated to giving practical and emotional support to all in the Debenham area who care for those with dementia”
    - Debenham probably the most advanced dementia-friendly community in UK, ahead of government targets; and seen as at cutting edge
    - Debenham Project’s aspiration to increase contact percentage from 50% to 70%

Research: Rationale

- This research uses a targeted, person-centred and conversational approach to elicit:-
    - The experience of (and the learning from) caring for and witnessing memory loss/dementia and its evolution
    - The pros and cons of early diagnosis & early engagement with services
    - The help and services that are needed in/near Debenham

- It will provide solid, specific (albeit local) data to
    - Assist the Debenham Project to improve on what it already does
    - Compare the assumptions behind national, regional & Suffolk policy and thus help test their robustness.

Methodology: Programme

- July-Dec 2012: Developing and evaluating a methodology
  - The methodology developed appears to be complete and potentially sufficient for use by others seeking to engage with people, in a non-prescriptive and personalised way, in this and other areas of research.

- Jan-July 2013: Rolling out the methodology:
  - Gathering data; initial analysis; provisional conclusions

- Aug-Oct 2013: Testing data & refining conclusions
  - Also awareness & publicity campaign; reporting & disseminating results

Methodology: Research Groups

1. Family Carers known to Debenham Project
    - Questionnaire
    - Face-to-face interview
    - Data quantitative and qualitative
    - Core data will be from questionnaires
    - Narrative data from interviews will add depth

2. Debenham Project Volunteers
    - Questionnaire & some interviews
    - Supportive data

3. Professionals
    - Interviews
    - Fleshing-out & interrogating narrative
    - GPs: interviews - dementia journey & early indicators

The process – outcomes so far (1)

- Family Carers:
  - 41 questionnaires sent out in total
  - 37 completed and returned (90%)
    - 2 unable to complete due to illness
    - 2 not the immediate carer

  - 32 interviews taken place out of poss 37 (78% of universe or 86% of responders)
    - 1 no-response to request
    - 2 yet to be done
    - 2 carers/cared-for too far away to be possible or relevant

Process outcomes so far (2):

- Volunteers:
  - 16 questionnaires to be despatched
  - Two further tranches to be identified
  - c.10% of total will be interviewed

- Professionals
  - 12 out of 13 interviews arranged are completed
  - Additionally c.3 GPs yet to be interviewed
  - Target group are from Health, Social Care & Vol Orgs

Some headline statistical data (1)

Age – Primary/Other family Carer (31 respondents)	**Under 70**	52%
	71-80	26%
	81-85	6%
	86-90	16%
	91+	0%
Age – Cared-for (31 responders)	**Under 70**	0%
	71-80	29%
	81-85	29%
	86-90	29%
	91+	13%
Health – Carer (25 responders)	**Excellent to good**	56%
	Fairly good to moderate	36%
	Poor	8%
Health – Cared-for (20 responders)	**Excellent to good**	50%
	Much improved	5%
	Moderate	15%
	Poor	25%
	Rapid decline & death	35%

Some headline statistics (2)

Suitability of present accommodation (26 respondents)	**Yes** 69% **Yes at present/mostly** 23% **Not now** 4% **N/a (eg due to decease)** 4%
First signs (multiple responses)	**1st – Memory loss** (17%) **2nd – Difficulty with familiar tasks**(12.5%) **3rd – Changes in mood/behaviour** (10%)
First turned to for help	**GP** 39% **Family/Friend/Colleague** 39% **Professional** 20% **Vol Org** 2% **Debenham Project** 2%
Could signs have been noticed earlier? (32 respondents)	**Yes** 31% **Possibly/probably** 22% **No/probably not** 34% **Don’t know** 13%

Some headline statistics (3)

82% Received diagnosis (NB of this fig, 22% diagnosed after treatment of another health issue)	from:- **Consultant** 72% **GP** 12%
Did diagnosis make difference?	**Yes/Yes possibly** 43% **No** 31% **Yes & No** 23%
Offered help as a result?	**Yes** 42% **No** 35% **Not really** 13% **Insufficient or late** 9%
What offered or from whom?	**List of orgs to contact** 16% **Benefits, OT, GP, Deb Proj** **Alz Soc, Local Charity,** **Social Care** } 8% each

Some headline statistics (4)

What encourages/ discourages seeking help?	**11 responses re ‘encourages’** (range from desperation, through info & leaflets in GP surgeries, to discussion with those who have been through similar experience) **32 responses re ‘discourages’** (10 were emotional reasons; 15 practicalities; 7 were reactional, esp. of others)
Knowing what you know now, what are the benefits/disadvantages of early diagnosis?	**31 benefits & 10 disadvantages given; and of the total of both:** **20% - Enables early planning** **15% - Confirms issue** **12% - Enables early help/treatment** **7% - Left with traumatic prognosis** **5% - None**

Some headline statistics (5)

Would earlier support have helped?	**Yes/possibly** 61% **No/prob not** 23%
How has the Debenham Project helped?	**Contact with other people** 24% **Support** 21% **Advice & info** 12%

Qualitative data: initial observations*

The person with memory loss, the carer and the journey

- **Each memory loss/dementia journey was different**
- **There was a very high level of commitment among the carers to the person**
- **The responding carers' lifestyle has changed significantly**
- **Most of the responders evinced a determination to continue caring for as long as possible at home**
- **The profile of the respondents was predominantly one of relative financial adequacy**
- **The loneliness of carers was evident**

***** ***From the analysis of Phase One results***

Qualitative Data: initial observations 2

Obtaining a diagnosis & engaging with services

- **A sheer lack of knowledge was apparent among carers and the person they cared for**
- **This lack of knowledge was particularly evident at the beginning, but also further into, the memory loss journey**
- **A heavy reliance on their own initiative and their own research was apparent among some carers**
- **Patchy access, provision and co-ordination of services was very apparent**
- **A large part of all those cared for had received a diagnosis from a consultant**
- **There was a clear benefit reported by responders in favour of seeking early diagnosis**
- **Significantly more considered it would have helped or possibly helped to have received support earlier**
- **Real gratitude for the Debenham Project was expressed.**

Interim conclusions - 1

Methodological

- We are still analysing data gathered in the (larger) Phase 2, but to date it appears largely to confirm the conclusions from Phase 1, while adding to them, as will be reported in the near future
- The qualitative data gathered from the structured interviews of family carers will provide additional depth to our research and conclusions
- Also, the narrative information being gathered from professionals and volunteers will give still further breadth and context to the results
- We will present the final conclusions in our future reports

Interim conclusions - 2

Issues arising

- Our data reveals that many respondents have not felt supported but rather have felt isolated, perplexed and ignorant and thus have either had to fall back on own resources (initiative, family etc) or wait for a crisis

- Many reported too many agencies to deal with – so one gateway is needed

- Provisionally, it seems the need is to ensure people have the knowledge and tools to identify what they need at the right time

- Likewise responsive, adequate and trusted local services, advice, care & support are required

- There is a large question as to whether services exist/will exist in sufficient depth and number to cope with demand and need

Interim Conclusions - 3

- The Dementia Advisory Service does not appear to have the capacity to be the gateway, despite being set up to this end
- The respondents appear to see the GP as the prime initial point of contact, although there are concerns
- The data so far analysed casts doubt over the Government’s approach of the Diagnosis as the gateway

Next Steps

- Complete carer interviews
- Complete analysis of carer consultation
- Produce interim report
- Undertake volunteer questionnaire & interviews
- Complete professionals interviews